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A Study of the Relationship between Health and Subjective Well-Being in Parkinson's Disease Patients

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ABSTRACT

Objectives: Governments are turning their attention to evidence on subjective measures of well-being to inform policy decisions. In the context of health, there is, therefore, growing interest in understanding how measures of health-related quality of life relate to subjective well-being and whether subjective well-being could provide a basis for resource allocation decisions in the future. This study investigates the relationship between health-related quality of life, as measured by the EuroQol five-dimensional (EQ-5D) questionnaire, and subjective well-being in Parkinson's disease. **Methods:** A paper questionnaire including the EQ-5D questionnaire, four key subjective well-being questions taken from the Integrated Household Survey in England, and other demographic details was distributed to people with Parkinson's disease in the United Kingdom. Responses were used to estimate multiple regression models explaining subjective well-being using the EQ-5D questionnaire index (UK weights), EQ-5D questionnaire dimensions and the visual analogue scale, and patients' sociodemographic characteristics. **Results:** A total of 199 responses were received. Combining visual analogue scale and EQ-5D questionnaire dimensions, especially anxiety/depression and, to a lesser extent, mobility, yielded the best-fitting models (adjusted R^2 range 0.36–0.53). Patients with Parkinson's disease living in care homes report lower levels of subjective well-being than do those living alone. These effects are not captured by the health-related quality-of-life measures in the analysis. **Conclusions:** Usual health-related quality-of-life measures can partially explain different well-being dimensions, yet they fail to capture part of the broader impact of disease on subjective well-being. Further empirical research into the relationship between subjective well-being and the EQ-5D Parkinson's disease longitudinally, and in different disease areas, is required, and further standardization of subjective well-being measures is recommended.

Keywords: EQ-5D, happiness, Parkinson's disease, subjective well-being.

Introduction

Governments across the world, including the UK government [1], and bodies such as the Organisation for Economic Co-Operation and Development (OECD) [2], are increasingly using evidence on subjective measures of happiness as a way of informing decisions about a wide range of public policies.

In the context of the health care sector, this has generated considerable interest in understanding how measures of health-related quality of life (HRQOL), which are widely used to inform decisions about pricing and reimbursement of health care technologies, relate to these measures of happiness or subjective well-being (SWB), and whether the latter might provide a basis for resource allocation decisions about health care in the future. This raises fundamental questions about what the purpose of health care is—to improve health or to improve happiness—and how these outcomes are best measured. For example, does the EuroQol five-dimensional (EQ-5D) questionnaire [3]—a generic measure of HRQOL that is recommended by the National Institute for Health and Care Excellence for use in evidence submitted to its health technology assessment process [4] and widely used internationally—capture some aspects of SWB? Which specific dimensions of the EQ-5D questionnaire relate to which measures of SWB? What aspects of SWB are missed by the EQ-5D questionnaire?

Some evidence on these questions is available. For example, a number of articles have attempted the use of SWB in *valuing* HRQOL states described in terms of the EQ-5D questionnaire and the SF-6D (as an alternative to current approaches used to value HRQOL states, such as the time trade-off [TTO]) [5–8]. Studies have also explored the extent to which various conditions contribute most to unhappiness [9]. To date, however, there has been little detailed examination of the relationship between dimensions and levels of the EQ-5D questionnaire (the EQ-5D questionnaire profile) and SWB by disease area; how patients' overall assessment of their own health on the visual analogue scale (VAS) relates to their self-reported SWB; and how these relationships differ across different aspects of SWB that might be measured.

Answering these questions is complicated somewhat by the lack of standardization in the use of the term SWB, the "new science" of SWB, as Layard describes it [10], having emerged relatively recently.

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For instance, the terms “happiness” and “subjective well-being” are often used interchangeably [11], although they are not identical according to most definitions. For example, happiness has been described as equivalent to life satisfaction, quality of people’s lives [11], or experienced utility [12]. However, SWB is frequently used as an umbrella term for how we feel (“affective happiness”) and think (“evaluative happiness” or “rewardingness”) about life [11]. Recent recommendations from the OECD [13] distinguish three different components of SWB: evaluative (reflective assessment of life “as a whole” or an aspect of it), affective (experience or feelings), and eudaimonic (functioning and realization of the person’s potential). Many different instruments have been developed to measure the various nuanced definitions of SWB. A comprehensive collection of the available instruments can be found in Helliwell et al. [11], and different guidelines providing advice on the collection and use of such instruments can be found in the OECD [13]. In this article, we viewed SWB as a broad concept that encompasses the three components.

In the United Kingdom, subsequent to a public consultation and advice from academics, the following SWB questions on an ordinal scale of 0 to 10 were defined for inclusion in the ongoing Integrated Household Survey beginning in April 2011 [14]:

1. Overall, how satisfied are you with your life nowadays?
2. Overall, to what extent do you feel that the things you do in your life are worthwhile?
3. Overall, how happy did you feel yesterday?
4. On a scale on which 0 is “not at all anxious” and 10 is “completely anxious,” overall, how anxious did you feel yesterday?

Question 1 is intended to capture the evaluative component. Question 2 represents the eudaimonic dimension. Questions 3 and 4 may be the basis for the second dimension (“affective”) in terms of positive and negative affect [11].

SWB determinants suggested by Helliwell et al. [11] embrace a wide variety of factors, for example, income, quality of governance, day-to-day joys, trust in one’s community, and having someone to count on in times of difficulty. Among all the factors influencing SWB, health obviously plays an important role, and HRQOL is frequently considered as a key dimension of SWB. Because SWB is a broader concept, and captures the individual’s own experience of his or her well-being, advocates of SWB would argue that using SWB to value health improvements could in theory address many of the limitations of measures of HRQOL. For example, SWB has the potential to be used more broadly as a measure of benefit across different sectors (e.g., across health and social care services) because arguably increasing well-being should be the ultimate goal of most, if not all, government policies whether in health or in any other sector. Thus, concerns about whether widely used measures of HRQOL—such as the EQ-5D questionnaire—are missing dimensions of health that are relevant to patients also is addressed because individuals would implicitly include these in their own assessment of SWB. How SWB relates to HRQOL, and particularly to the EQ-5D questionnaire, however, has not been widely studied.

The primary aim of this exploratory study was therefore to investigate the relationship between HRQOL (as measured by both the EQ-5D questionnaire profile and patients’ overall rating of their health on the VAS or EQ-VAS) and SWB scores (on the four key Office for National Statistics (ONS) questions described above) in a given health condition. The population chosen for this analysis is patients with Parkinson’s disease (PD). PD is a progressive neurodegenerative disorder affecting approximately 120,000, or 1 in 500, people in the United Kingdom. The condition is characterized by disabling motor symptoms, including tremor, rigidity, and slowness of movement, often accompanied by nonmotor symptoms, including pain, depression and anxiety, constipation, and fatigue.

This patient cohort is interesting for a number of reasons. First, although the EQ-5D questionnaire appears to work reasonably well as a measure of HRQOL in PD [15], no previous research explored how the UK SWB measures perform in this group of respondents. Second, PD is a good example of a disease area for which the usual measures of HRQOL may fail to capture part of the wider effects of the disease on SWB. For instance, SWB determinants suggested by Helliwell et al. [11] as “having someone to count on in times of difficulty” or “trust in one’s community” may not be captured by usual measures of health or utility. We analyzed the degree of correlation of proxies for these determinants and SWB for patients with PD, with and without controlling for health-related factors. If significant differences were found, this would be an indicator that the extent to which a disability affects subsequent well-being depends not just on the severity of the disability but also on other factors, and the extent to which patients are enabled in maintaining their social connections. If so, the article would provide some insights into the appropriateness of using SWB measures as a complement for health resource allocation in the near term.

Methods

The Questionnaire and Data Collection

A paper questionnaire was developed for self-completion by individuals with a diagnosis of PD in the United Kingdom. The questionnaire included the following items:

1. Demographic characteristics questions (age range, sex, years since diagnosis, marital status, employment status, household situation, and education). Income data were not collected because of concerns that this might adversely affect the response rate [16]. A tick-box format was used for ease of completion.
2. The three-level EQ-5D questionnaire instrument [3], including both the patients’ EQ-5D questionnaire health profile and the patients’ overall assessment of their health on a VAS (the EQ-VAS, from 0 to100, representing worst-possible and best-possible health, respectively). The EQ-5D questionnaire health profiles can also be summarized by a single number representing the relative value of that health state on a scale anchored at 1 (full health) and 0 (dead). The value set used for this purpose in this study is the UK value set reported by Dolan et al. [17].
3. The four SWB questions taken from the Integrated Household Survey, as shown in the Introduction, and adapted from the verbal interviewer script into a written format to enable self-completion.

Two versions of the questionnaire were developed, in which the order of the EQ-5D questionnaire and SWB questions was alternated (50:50 split) to control for ordering effects.

Two strategies were used to contact potential participants:

1. Attendance at seven local Parkinson’s UK support group meetings and three larger regional Parkinson’s UK forum meetings in the southeast of England where objectives of the research were presented and questions answered. Questionnaires were then distributed to interested members.
2. An e-mail sent to the Parkinson’s UK’s online research network inviting interested members to request a questionnaire by post. Stamped, addressed envelopes were provided for returns. Participants were assured that their responses would